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May 18, 2015

The Honorable Fred Upton
Chairman
Committee on Energy & Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Joe Pitts
Chairman
Committee on Energy & Commerce
Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

The Honorable Diana DeGette
Ranking Member
Committee on Energy & Commerce
Subcommittee on Oversight & Investigation
U.S. House of Representatives
Washington, DC 20515

Dear Chairmen Upton and Pitts and Ranking Members Pallone, Green, and DeGette,

On behalf of the entire Parkinson's community, the Parkinson's Action Network (PAN) strongly supports the inclusion of the National Neurological Diseases Surveillance System (Section 1122) in the *21st Century Cures Act* and hope it will remain, as written, in the final legislation presented to Congress and ultimately signed into law. We are grateful for your support of this important priority.

PAN is the unified voice of the Parkinson's community advocating for better treatments and a cure. In partnership with other Parkinson's organizations and our powerful grassroots network, we educate the public and government leaders on better policies for research and an improved quality of life for Americans living with Parkinson's disease, for whom there is no treatment available that slows, reverses, or prevents progression.

We estimate that between 500,000 to 1.5 million Americans are living with Parkinson's disease but we do not have accurate information on how many are actually battling Parkinson's, and what causes the disease. This lack of core knowledge inhibits Parkinson's research, treatments, programs, and services. A national neurological surveillance system at the Centers for Disease Control and Prevention (CDC), as proposed in Section 1122 and the stand-alone bill, the *Advancing Research for Neurological Diseases Act* (H.R. 292/S. 849), will provide data on the epidemiology,

incidence, and prevalence of neurological diseases. Better data would allow for future planning of health care needs, detect changes in health practices, assess disease burden, promote education about neurological diseases, and, most importantly, support a wide range of research initiatives.

That's why this is a top priority of the Parkinson's community – the data collected under this system could truly be a game-changer for a deeper understanding of neurological diseases and provide critical information to researchers as they work on new treatments and the ultimate goal: cures.

Thank you again for your leadership on this provision and on the 21st Century Cures Initiative. If you have any questions, please contact Jennifer Sheridan Palute, PAN's director of policy, at jpalute@parkinsonsaction.org or 202-638-4101 ext. 112.

Sincerely,

A handwritten signature in black ink, appearing to read "Ted Thompson". The signature is fluid and cursive, with a large initial "T" and a long, sweeping underline.

Ted Thompson, J.D.
Chief Executive Officer

Cc: Representative Michael C. Burgess and Representative Chris Van Hollen